CULTURE, DEATH AND DYING

HIS LECTURE 9

29/11/12

Moira Kelly

Though death challenges our existence, it also gives meaning to our lives. It may be the instrument of absolute separation, but it is also the key to all communication.

Simone de Beauvoir (*The Prime of Life* 1965: 606)

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Learning objectives

- Consider how death and dying may be viewed as social constructions
- Describe and review cultural aspects of death and dying
- Critically review the concept of the 'good death' and it's relevance to global health

Life expectancy and the demographic transition

- Average life expectancy worldwide
  - 1955 = 48 yrs
  - 1995 = 65 yrs
  - 2025 = 73 yrs
- Shift in causes of death from infectious disease to degenerative conditions
- http://gamapserver.who.int/gho/interactive_charts/mbd/life_expectancy/atlas.html

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The ageing of mortality (UK, ONS, 2012)

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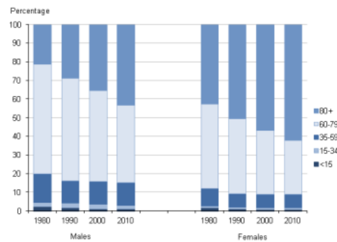


How is 'death' decided?

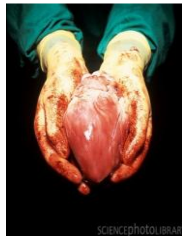
- Clinical death
- Brainstem death
- Social death

Death practices - Japan

- Culturally there is resistance to accepting brainstem death as clinical death
- Although legal since 1997, organ donation from dead donors is very low
- Distrust of doctors is also a factor

Tomomatsu (2012) – Heart transplantation in Japan

- < 10 heart transplants a year
- Influence of Japanese cultural expectations about the body + custom of reciprocal gift exchange
- Transplantation is associated with social stigma – for recipients and donors
- Brainstem death is an issue
- Using an organ for transplantation conflicts with attitudes towards the treatment of the dead body in Japan



Culture

- Shared experiences, beliefs and values
- Ethnicity is an important aspect of culture, but does not necessarily define us culturally
- We may have multiple cultural identities
- Our cultural experience is dynamic and subject to change

Death as culture

- Death and dying rituals express culture and community
- Social practices associated with death and dying create community
- Historically death was a shared event which brought people together

Death and the cultural transition (Bury, 1997)

- Demographic transition → 'cultural transition'
- We expect to live more predictable lives in the context of a relatively safe environment
- Emphasis on life planning and self-identity (Berger et al cf Bury, 1997)

The revival of death (Walter)

- The church – rituals surrounding death which primarily happened at home
- Medicine – $18^{th}/19^{th}$ centuries – advent of the hospital and development of medicine – bodies removed from the care of families and communities
- Sequestration of death

Cultural scripts for dying (Seale, 2000)

- May act as myths providing a sense of coherence in the face of suffering
- Scripts for proclaiming 'heroic self-identity' in the face of death
- Involves struggle and courage
- Unlike more traditional forms of heroism, this script includes a female heroics of emotional expression
- Control of major life events such as including dying is becoming a key feature of self-identity

Where do people die in the UK?

Place of death	All deaths (%) (2005-7)	Malignant neoplasm (%) (1998)
Hospital	58	56.5
Hospice	5	16.5
Care homes	16	3.4
Home	19	23.0
Other private houses	2	1.6

Awareness of dying (Glaser and Strauss, 1965)

- Ethnographic study of dying in US hospitals
- Identified communication as a key issue
- Awareness contexts:
  - Open
  - Closed
  - Suspicion
  - Mutual-pretence
- Current best practice takes open awareness as the ideal

Open awareness

- Tied to the emphasis on the individual as the locus of decisions and choices related to their death
- Informed by a predominantly individualistic way of managing the self in late modern conditions

Ethnography

- Observational studies – can be participant or non-participant
- Data collection – field notes, interviews, documents, other media
- Case study approach
- Analysis – descriptive (content – how do people die in hospital?) and in-depth (research question identified during data collection/analysis – how is communication about death socially organised?)

Developing theory

- Inductive approach
- Identify categories and themes
- Identify research problems to examine in the data
- Make comparisons across the data (constant comparison)
- Deviant cases (from your analysis) used to

No place for dying (Chapple, 2010 cf Arolker, 2011)

- Why are patients with little prospect of survival submitted to a compulsory process of rescue?
- Prioritising of technologically-driven health care focused, almost exclusively, on stabilising lives deemed salvageable
- 'rescue care' vs 'end of life care'
- Care of the dying treated as second-class

Medicalisation of death

- "Medicalisation" of dying
- regarding death as something to be resisted, postponed, or avoided
- Death as something to be managed and 'tamed'
- 'failure' of medicine?

Medicalization of death

We have witnessed in countries such as the UK specialisation and professionalization which has brought something of an expert takeover of death and dying in ways that have both dehumanized and removed them from everyday experience and consciousness.
(Conway, 2012)

How has modern medicine affected how people die?

- Doctors face problem of balancing **technical intervention** with a **humanistic orientation** to their dying patients
- Palliative care has come about as a response to calls for greater dignity at the end of life

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Privatisation of death in the UK

- Death individualised and secularised
- Reduced social support through family and community
- Death as an individual affair to be managed by experts and institutions

Medicalisation and the 'natural death' (Seymour, 1999)

- 'romantic' notions of the natural death?
- 'medical' and 'natural' assumed to be in polar opposition to each other
- Medical-technological intervention during dying → emblematic of inhumane and unnatural death
- Research in ITU – the meaning of 'good' or 'natural' death is subject to a process o interpretive construction and reconstruction

What challenges does the privatised, individual approach to dying present for 'culturally competent' care?

Hospices and palliative care

- St Christopher's Hospice – active approach to terminal illness → research, education + care for patient and family
- Palliative care has evolved as a medical discipline
- Emphasis on quality of life while dying
- Effective symptom control
- MDT approach – expertise of doctors, nurses and social workers
- Concerned with patients and relatives

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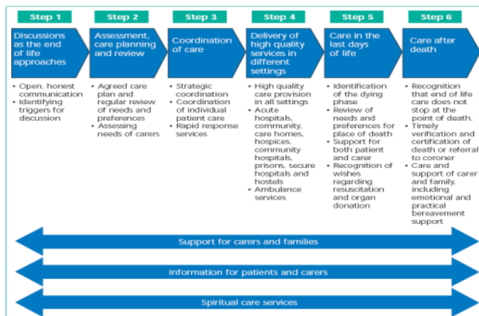
Awareness of dying 2011

- Gott, BMJ 'palliative care in acute hospitals'
- Terminal prognosis not routinely discussed with patients
- Discussions about adopting a palliative care approach to patient management were not often held with patients
- Primary care professionals confirmed that patients were often discharged from hospital with false hope of cure

Disadvantaged dying

- People with non-malignant diseases are the 'disadvantaged dying' (Poppel et al , 2003)
- Receive minimal or no palliative care
- Liverpool Care Pathway – developed as a way of making palliative care available to people dying in hospital

Liverpool Care Pathway – a controversial guideline...



LCP (guideline) as tick box exercise?

http://sweol.wordpress.com/2012/11/28/liverpool-care-pathway-has-become-a-tickbox-exercise-not-a-thoughtful-shared-process/

Media messages from the LCP story

Messages about the LCP

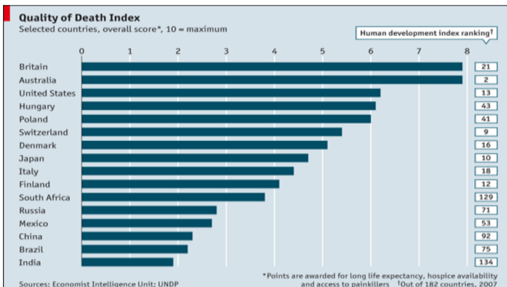
- Inappropriately shortens life?
- Abuse of vulnerable (older) people?
- Don't trust doctors and other health professionals?
- Cost cutting?

Impact of media story

- Saves lives?
- More people die in pain?
- Denial of death?
- Decreases the possibility of a dignified death for people who die in hospital?
- More people die hydrated?
- Defensive medicine?

Quality of death index

(Economist Intelligence Unit, 2010)



The good death

….I have… learnt that the "good death" that is the aim of modern palliative care is about much more than symptom control. It is, or should be, about enabling people to retain their dignity, to exercise choice, and above all to stay in control until their last moment.

Katona (*BMJ*)

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http://www.dyingmatters.org/

What would you consider most important about the care available to you if you were dying?:

To be surrounded by people I love
To be free from pain
To have spiritual support available
To be able to communicate
To be at home
To have medical support readily available

SEMINAR 9 – The 'good death

- In this seminar we will review how death may be considered as 'good' or 'bad' from medical and social viewpoints.
- Read the BMJ paper by Tony Walter in the set reading and write 200 words on what you would consider a 'good death' to be.
- Consider implications for individuals, families and communities as well as the role of healthcare.
- Read the posts of others and comment on at least one person's post.